Knowledge About Palliative Care in Cancer Patients

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Abstract

Background: Patient awareness plays an important role in integrating palliative care into the patient care process. Lack of awareness can create a negative attitude towards palliative care and affect patients' decisions during the treatment process. The present study was conducted to determine the level of knowledge about palliative care in cancer patients.

Methods: The descriptive-analytical study was conducted with a convenience sample of 103 cancer patients admitted to an oncology ward in Yazd, Iran, A three-part questionnaire including demographic information, sources of palliative care information and the Palliative Care Knowledge Scale (PaCKS) was used to collect data. All statistical analyses were performed using software SPSS 21.

Results: The mean age of patients was 36.2 ± 13.5 years. Of the total, 38.8% of patients received information about palliative care through the media and 36.9% from the treatment team. On a scale of 0 to 13, the mean PaCKS score was 6.7 ± 3.7 . A good level of knowledge was reported by 29.1% of participants; however 84.5% stated that they should leave other doctors at the time of receiving palliative care, 71.8% considered palliative care for patients in the last six months of life, 84.5% considered palliative care for patients with cancer, and 70.9% stated that palliative care encourages people to discontinue treatments aimed at treating their disease.

Conclusion: Our study found most cancer patients have a moderate to weak level of knowledge and considerable misinformation about palliative care, which highlights the importance of providing palliative care education. The development of training programs in this area could play an effective role in improving patients' knowledge of palliative care.

Background

Cancer is one of the most challenging diseases worldwide of the current century (1). After cardiovascular diseases and accidents, cancer is the third leading cause of death in Iran (2). It is predicted that by 2025, there will be more than 130,000 new cases of cancer in Iran (3). This disease is a potential threat to life and can have adverse effects on the physical, psychological, social, economic and overall quality of life of patients, with 60-90% of patients having physical symptoms and complications such as fatigue, nausea, pain, diarrhea, from loss of appetite and 40% experiencing symptoms such as anxiety and depression (4,5).

Palliative care is an interdisciplinary approach; the World Health Organization has introduced palliative care as a way to improve the quality of life of patients with incurable diseases and their families (6). Palliative care begins with the diagnosis of the disease and continues throughout the illness (7). Palliative care can prevent or relief of the patient's suffering through early identification and evaluation and treatment of pain and other problems of physical, psychological and social dimensions (8).

The integration of this palliative care in the care program of cancer patients is an essential component for care management (9). Although attention to palliative care is increasing today (10), many patients who can benefit from this type of care, never go to palliative care or receive it late(11) .In the United States the median time between palliative care referral and death was 72.5 days, with a mean 126.5 days(12).

While early referral to palliative care centers improves physical symptoms (dyspnea and fatigue), improves anxiety, reduces visits for immediate care(13), increases satisfaction with care(14), increases the tendency for death to occur at home(9), increase in survival time (10) , increase in quality of life(10, 14), reduces Emergency visits , reduces hospital admissions(9), reduction of depression(10). In contrast, patients who have not received palliative care at all or who are late to this type of care are more likely to receive invasive treatments, including chemotherapy, and their risk of death from treatment complications increases(15).

Often, palliative care is delayed until other treatments seem unresponsive, even though integrating this type of care during different stages of treatment can reduce the severity of symptoms. The initiation of palliative care at the time of diagnosis provides a supportive partnership for the treatment team and as the disease progresses, the need for palliative care increases (16).

Therefore, it is recommended that palliative care be started in the first 8 weeks after the onset of the disease (17)and the American Society of Oncology Guidelines recommend that palliative care be introduced and started at the onset of cancer for some patients. (18).In order to integrate palliative care more quickly into the process of caring for cancer patients, it is essential to identify barriers that prevent patients from being referred to palliative care centers; among the various barriers, failure to meet patients' information needs has been identified as a major barrier. (19) .Beerneart et al. stated 30% of patients with a predicted lifespan of less than 6 months had limited information about palliative care (20). Further, Zafar et al. reported that only 25% of patients with advanced cancer received information about palliative care (21); most patients stated they need written information about palliative care and do not have the necessary information about dimensions of palliative care (22).

Lack of awareness can lead to a negative attitude towards palliative care and be considered an obstacle to cancer treatment. The patient may be concerned about the interference of this type of care with cancer treatment (23). Some patients think that any patient who is referred to palliative care has reached the end of his / her lifespan(24).

Lack of palliative care education programs for patients and their families is a barrier that reduces use of palliative care (25).In fact, lack of information is an important challenge at present and should be investigated because cancer patients need to be aware of the goals and benefits of palliative care and have access to this information in various departments of oncology(26). It is very important to identify patients' awareness in this regard and to consider patients' decisions about type of care will use for the remainder of their lives(27).

Some patients referred to palliative care centers, due to lack of awareness, think that their death is imminent, and many of these patients consider these centers as pain treatment centers (28) and misinformation has a negative effect on patients' decisions during Treatment process (29). In addition, unfamiliarity with palliative care can prevent the patient from being admitted to palliative care and resist the referral of a physician to palliative care centers(30) . Focusing on the fact that palliative care is provided sporadically and in a limited number of centers in Iran in recent years, cancer research centers and the Ministry of Health have focused on palliative care, especially for cancer patients. Therefore, it seems that the development and progress of these programs is not far away, but there is still a long way to go to reach the desired situation, which requires collective and multi-purpose efforts(31).

Determining the level of patients' awareness of palliative care and identifying their needs can play an important role in encouraging use of palliative care services. Developing educational resources related to palliative care for patients requires a lot of information about existing knowledge to identify aspects of lack of knowledge (32). Therefore, the present study was conducted to determine the level of knowledge about palliative care in cancer patients.

Methods

The descriptive study was conducted in Yazd (a city in the center of Iran). After obtaining approval from the institutional ethics committee (IR.SSU.MEDICINE.REC.1399.055), patients with cancer admitted to the oncology ward of Shahid Sadoughi Hospital in Yazd with written informed consent were enrolled in the study.

Inclusion criteria were: having a diagnosis of cancer, 18 years and older, Persian speaking, literate, willing to participate in the study. Patients with cognitive disorders were excluded from the study. The sample size was determined as 94 individuals according to the study of Kolzo et al (33) based on significance level of .05 and power of 80% . Considering the probable 10% dropout , sample size calculated 103 individuals .

A three-part questionnaire was used to collect data: 1) Questions related to demographic information (gender, age, married, native of Iran, education, employment status, type of disease, duration of illness), 2) One question about the sources of information on palliative care, and 3) Palliative Care Knowledge Scale (PaCKS). The PaCKS was designed by Kozlov et al. (2017). It has 13 true/false questions. The score of the questionnaire is 0-13 and the higher score indicate the more knowledge. A score of 3-6 was considered a weak level, 7-10 a moderate level and 11-13 a good level. The KR-20 was .71, which indicated adequate internal consistency among the items. The ICC was .70 (95% CI.56, .80), which indicated reasonable stability. Construct ,convergent and discriminative validity of the PaCKS confirmed were (30).

In this study, with the permission of the instrument developer, this tool was translated from English to Persian by two independent translators simultaneously. The translators tried to translate the words within the framework of Persian culture. In the second step, the translations were compared and reconciled into

a single translation. The translations were then compared and the discrepancies were identified and corrected based on additional expert opinions. In the third step, the Persian version was given to two translators whose native language was English to be translated from Persian to English. After receiving the translations, reviewing the translations by experts to resolve discrepancies and merging the translations, the final translation prepared was sent to the device developer to verify the compatibility of the submitted version with the original version. After receiving the tool manufacturer's comments and translating approval, the final Persian version entered the psychometric testing process for face validity, content validity, and instrument reliability.

In order to determine the face validity within the Iranian context, after obtaining informed consent and stating the purpose of the study, the questionnaire was given to ten cancer patients admitted to the oncology ward to ensure the transparency of the questions. In the next stage, to check the content validity, the questionnaire was given to ten professors of the Faculty of Nursing and Midwifery of Shahid Sadoughi University of Medical Sciences, Yazd. Content validity ratio and content validity index were 0.72 and 0.79 respectively. The reliability of questionnaire was calculated using KR-20 and was 0.80, an acceptable estimate of reliability.

Results

One hundred and three questionnaires were completed by the study participants. Mean age of the participants was 36.2 ± 13.5 years, 68.9% were natives of Iran, 63.1% were male, 57.3% were married, 58.3% had education at the high school and 35.9% were employed (Table 1). Type of cancer was states as leukemia for 39.8% of participants (Table 2) and the mean duration of cancer was 2.4 ± 1.2 years. The sources of information on palliative care were: 38.8% media, 36.9% treatment team, 28.2% relatives and acquaintances, 25.2% Internet search, 19.4% books and educational pamphlets.

The mean score on the PaCKS 6.7 ± 3.7 . In terms of level of awareness, the results showed that 29.1% (n=30) had a good level, 50.5% (n=52) had a moderate level and 20.4% (n=21) had a weak level.

More than half of participants (54.1%) considered the purpose of palliative care to address psychological issues caused by an incurable disease, 64.1% stated that the stress caused by an incurable disease can be managed with palliative care, 53.3% considered palliative care to be useful in controlling the side effects of medical treatments, 84.5% said that people should leave other doctors at the time of receiving palliative care, 71.8% said that palliative care was only applicable to people who were in the last six months of life, 84.5% stated that palliative care is only for cancer patients, 59.2% stated that the place of receiving palliative care is the hospital.

27.2% stated that palliative care was designed specifically for the elderly, 70.9% considered palliative care as a team care approach, 51.4% stated that the purpose of palliative care was to help people better understand their treatment options. 70.9% stated that palliative care encourages people to discontinue treatments aimed at treating their disease. 50.5% said that the goal of palliative care was to improve a

person's ability to participate in daily activities. 50.9% stated that palliative care helps all family members to cope with incurable disease (Table 3).

Discussion

To our knowledge, this study is the first study to investigate the awareness of cancer patients about palliative care in Iran. This is important because identifying gaps in patients' awareness of palliative care can help with successful implementation and the resultant benefits to patients and families(34).

Among the participants in this study, the majority did not have a good level of knowledge about palliative care. Similarly, 81.3% of oncology patients in London (35). 63.1% of cancer patients in Japan(36), 61.1% of advanced cancer patients in the United States(37), 60.7% of patients with cancer in Ethiopia (38) and 54% of patients with advanced cancer in Singapore (39) do not know enough about palliative care or hospice care. Together, these findings are worrying because the field of palliative care is advancing rapidly, yet little progress has been made on at the level of patient awareness about palliative care (34).

The results showed that only half of the patients are aware of the goals of palliative care. El-Jawahri et al. Stated that patients consider hospice care to help alleviate patients' symptoms and the role of this type of care is to provide psychological and spiritual support for the patient and the patient's family and provide medical care for patients(40).In Saudi Arabia, a survey of public awareness of palliative care found that most people see palliative care as improving patient quality of life, reducing physical suffering, providing patient comfort, reducing patient pain, and maintaining patient dignity (41) also a survey of public opinion in Northern Ireland found that most people see the goal of palliative care as reducing pain, providing comfort and maintaining dignity (42).In Sweden, a similar study found that the goal of palliative care is to provide end-of-life care, pain relief, dignity, and easy death (43). In the United States, a study of people's knowledge showed that people knew the purpose of palliative care was to help the patient's family to cope with illness, emotional social support, pain management, and other physical symptoms (44).Overall, it seems that being aware of the goals of palliative care in various studies is the result of expanding the provision of palliative care and introducing it to patients in recent decades,

Another finding of the present study was that most participants stated that people should give up other physicians when receiving palliative care, and more than half of the patients reported that palliative care encouraged them to discontinue treatments aimed at treating their illness. In the United States, a study of knowledge and beliefs about palliative care showed that most people in general think that they should stop other treatments prescribed by physicians when starting palliative care(45).

In the present study, most patients stated that palliative care is only for people who are in the last six months of their lives and is exclusively for cancer patients. Consistent with this finding, a review study found that a common misconception about palliative care is that this type of care is for patients who have only 6 months left to live(34).Other study reported that participants considered palliative care to be exclusive to cancer patients (46). From the UK, a study on knowledge of palliative care of the general public found that participants thought that palliative care is for people who are dying, patients who are in

the last days of their lives, or people with an incurable disease (47). These findings indicate that the target group for palliative care is not yet well known to both the general public and oncology patients, and that awareness of who can benefit from palliative care should be a priority of palliative care center education efforts.

Regarding the place of receiving palliative care, half of the patients stated that they should go to hospitals to receive palliative care, indicating that they were not aware of the various centers that provide palliative care. Consistent with this finding, Chosich et al. reported that 39% of cancer patients knew that palliative care specialists could provide palliative care and 20.8% of the patients knew that palliative care could be provided by palliative care units, hospital-based counseling and outpatients units (48). Hirai et al. stated that 18.6% of the patients who were aware of palliative care were unaware of the centers that provide this type of service (36) and in the study by Tebra et al., less than half of the patients knew the centers providing palliative care (49).

The consistent findings in this and prior studies show that, despite the several decades that have passed since the inception of palliative care, familiarizing patients with the options for specialists and centers providing palliative care has been neglected; this lack of awareness may be interfered with timely referral and use of palliative care.

Results showed that the media, treatment team, relatives and acquaintances, Internet search and reading books and educational pamphlets were introduced sources of information on palliative care, respectively. Other studies have reported the use of the media, relatives and friends, treatment team members as sources of information about palliative care (43, 50). It is noteworthy that in the present study, the use of media was the most common, which may indicate a weakness in the role of health care providers in the field of palliative care. With the efforts of care system managers to explain the role, important care providers in the field of patient education, and purposeful planning care by providers can be the first source of information for patients prior to the time when they will need and benefit from palliative care.

Books and educational pamphlets related to palliative care were reported as the least common source in the present study. Similarly, Taylor et al., found that less than 13% of inpatient units, 7% of outpatient units and 25% of daily chemotherapy units have written materials available on palliative care. To increase patients' awareness of palliative care services and eliminate misconceptions related to palliative care, it is imperative to prepare appropriate educational leaflets and make them available to patients in oncology departments to increase patient information and help start a discussion about the role of palliative care and its' integration into the plan of care in a timely manner (26).

Limitations

This study has some limitations, so the generalization of the results should be done with caution. The study participants were selected from only one university-affiliated teaching hospital, which is a center for providing services to cancer patients in Yazd. Therefore, further studies with random sampling from different centers providing services to cancer patients and from different cities can provide broader and

more reliable information in order to determine the awareness of cancer patients of palliative care and identify knowledge deficits. Also, in this study, patients with different types of cancer participated, so it is not possible to identify the state of patient's awareness with a specific type of cancer; further studies should be done specifically according to the type of cancer.

Conclusion

Overall, the findings of this study indicate misinformation and insufficient awareness of cancer patients about palliative care and highlight the importance of providing palliative care education. The development of educational programs to familiarize cancer patients with palliative care, its' benefits, how it is provided, how to access different centers for palliative care providers and members of the palliative care team.. It can play an effective role in improving patients' awareness of palliative care and reducing the lack of knowledge, an important obstacle to the effective use of palliative care.

Abbreviations

PC: palliative Care

Declarations

The authors declare no conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Authors' contributions

N.S and M.R were involved in the conceptualization and design of the study as well as the drafting of the manuscript and tables. A.D and I.B and F.T were involved in data collection and analysis. All authors contributed to and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed in this study are available from the corresponding author upon reasonable request.

Ethics approval and consent to participate

The ethical approval code was IR.SSU.MEDICINE.REC.1399.055.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no conflicts of interest.

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Tables

Due to technical limitations, table 1-3 is only available as a download in the Supplemental Files section.

Supplementary Files

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